

Early Treatment for HIV Act: Expanding Care through Medicaid

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Introduction

The Early Treatment for HIV Act (ETHA) is proposed legislation that was introduced in the 106th, 107th and 108th Congresses. It was introduced in the Senate of the 109th Congress and both the House and the Senate of the 110th Congress.^{1,2,3,4,5} ETHA, if passed, will provide states the option of expanding Medicaid coverage to individuals living with HIV. The proposed legislation is modeled after the Breast and Cervical Cancer Prevention Treatment (BCCPT) Act of 2000. The BCCPT Act amended Title XIX of the Social Security Act giving states the option of expanding Medicaid coverage to women who were found, through early intervention programs, to have breast or cervical cancer. Thus, it provided these women with lifesaving medical care early in the disease.⁶

ETHA, in a similar manner, would provide resources to pay for early intervention, treatment, and healthcare for people living with HIV. Currently, most individuals with HIV/AIDS who qualify for Medicaid do so because they are certified as disabled after they have received an AIDS diagnosis. Unfortunately, this means that many people are too sick to benefit from current therapies, since, according to the standard of care guidelines, they are past the recommended point to begin treatment.⁷ Successful passage of ETHA would allow more HIV positive people to receive treatment at earlier stages of the infection.

Medicaid, Medicare and HIV/AIDS

To understand ETHA, it is first important to review some of the basic components of Medicaid. Created in 1965 under Title XIX of the Social Security Act, Medicaid is an entitlement program that is jointly funded and administered by the federal government and the states. Unlike the spending for federal discretionary programs, such as the Ryan White CARE Act (RWCA), federal Medicaid spending is not set in advance or on an annual basis by Congressional appropriations committees. There is no set limit on the amount of funding available each year to the Medicaid program, and there is no limit to the number of eligible beneficiaries. Actual Medicaid spending fluctuates

with the cost of health care and with the number of people enrolled, which depends on a variety of factors including the poverty rate. Medicaid covers three main groups of low-income Americans: the elderly, the disabled, and parents and children. Individuals who meet this and other financial eligibility criteria are entitled to have their respective states make payments on their behalf for certain covered services. State participation in Medicaid is voluntary; since 1982, however, all states have elected to participate. States are entitled to matching funds from the federal government for their costs in covering eligible individuals, and the federal government pays at least one half of Medicaid costs through a Federal Medicaid Assistance Percentage (FMAP). The FMAP is a matching rate paid to states to reimburse Medicaid expenditures. By law, the FMAP cannot be lower than 50 percent or greater than 83 percent of a state's Medicaid expenditures.⁸

All states provide Medicaid coverage to individuals who meet specific income and asset requirements. These requirements vary by state, but typically income requirements are below 133 percent of the federal poverty level and asset levels are capped at \$2,000.⁹ States must offer a basic benefits package that is outlined by federal law and falls under broad, general guidelines. These guidelines stipulate that each state must establish its own eligibility requirements; determine the type, amount, duration, and scope of services; set the payment rate for services; and administer its own program.¹⁰ Although Medicaid benefits vary greatly from state to state, all state Medicaid programs cover some level of hospital, physician, nursing home, prescription drug, and long-term care services.

Medicaid is a vital source of healthcare for people with HIV. It is estimated that the program covers 55 percent of all people living with AIDS and 90 percent of all children living with AIDS who are receiving medical care.¹¹ In fiscal year 2006, the federal government spent \$6.3 billion on HIV/AIDS care through the Medicaid

program.¹² As the largest direct payer for medical care for people with AIDS, Medicaid is a critically important program. Yet despite its importance, the structure of the Medicaid program is often ill-suited to meet the needs of people living with HIV/AIDS. Further, poor Americans with HIV, but not AIDS, are currently not eligible for health care under the Medicaid program, since income is only one test for Medicaid eligibility.

Most people living with HIV/AIDS who qualify for Medicaid do so because, in applying for Supplemental Social Security (SSI), they have been determined as disabled. Qualifying for SSI payments requires individuals to meet the definition of disability as put forth by the Social Security Administration—the federal agency that administers SSI. This definition states that an individual must be unable “to do work that [he or she] did before and we decide that you cannot adjust to other work because of your medical condition(s). Your disability must also last or be expected to last for at least one year or to result in death.”¹³ Social Security pays only for total disability. No benefits are payable for partial disability or for short-term disability. For most people living with HIV, the Social Security disability definition means that they will not be eligible for services until their immune systems have declined to the point of an AIDS diagnosis and/or they are no longer able to work.

The requirement of the Social Security Administration to have a “disability status” to qualify for Medicaid results in a dilemma for most people living with HIV. Current federal guidelines call for early access to medical care and treatment, including the use of combination antiretroviral therapy.¹⁴ Advancements in treatment and the use of antiretroviral therapies come at a high price. Treatment with antiretroviral therapy costs between \$13,680 and \$22,080 annually and with the cost of monitoring patients and other services related to antiretroviral therapy rises to \$24,000 to \$27,600.¹⁵ Low-income individuals, many of whom are uninsured or underinsured, are making up greater portions of the epidemic. Yet, they are simply unable to access and pay for life-prolonging medication and care.

There have been attempts, both administrative and legislative, to decrease the limitations of Medicaid for people living with HIV. These attempts, however, have been generally unsuccessful. One of these options is the Section 1115 waiver of the Social Security Act.

Section 1115 permits the Secretary of the U.S. Department of Health and Human Services to authorize demonstration projects which are likely to assist in promoting the objectives of Medicaid through the use of waivers to parts of the Medicaid program.¹⁶ These waivers allow states to create demonstration projects that explore new Medicaid policies and uses, including expanding eligibility to those who might not otherwise be entitled to Medicaid. To date, ten states have applied for Section 1115 waivers to expand Medicaid coverage to people living with HIV who are not legally considered disabled, but otherwise meet state criteria for Medicaid eligibility. Only two of the states (Massachusetts and Maine) and the District of Columbia have received final approval¹⁷.

Another administrative program that tried to expand Medicaid coverage to non-disabled HIV positive people is the Ticket to Work and Work Incentives Improvement Act of 1999.¹⁸ Title II of this legislation required the Secretary of the U.S. Department of Health and Human Services to establish demonstration projects under which states could provide benefits similar to Medicaid’s to workers with potentially severe disabilities—conditions that, as defined by the states, are reasonably expected to cause a level of disability that meets Social Security’s requirements. The Ticket to Work program was not successful at expanding access and after its six-year term ended, the program was shelved.

While there have been a few attempts to expand Medicaid coverage for individuals living with HIV/AIDS, the optional nature of the Ticket to Work legislation and the budget neutrality requirements of 1115 waivers have ultimately left many low income individuals living with HIV unable to qualify for health care under Medicaid. The result is that many of these low-income individuals do not have access to public or private health insurance and are increasingly relying on services provided through Ryan White CARE Act programs. There are some new benefits for people living with HIV/AIDS accessed under the recently enacted Medicare Modernization Act which has come to be known as “Part D.”

Part D gives prescription drug coverage to an estimated 100,000 people living with HIV/AIDS who are receiving Medicare benefits. Medicare eligibility is determined by being 65 or older or being on Social Security Disability Income (SSDI) for 24 months. SSDI is a benefit for those who cannot work due to disability and have acquired a

sufficient number of work credits to qualify for Social Security payments. The majority of Medicare eligible people living with HIV/AIDS, about 70%, also qualify for Medicaid¹⁹. The narrow eligibility requirements for Medicare mean that the majority of people living with HIV/AIDS cannot access it.

ETHA Legislation

ETHA was introduced in an attempt to provide treatment earlier in the course of HIV disease progression for low income Americans living with HIV. Originally introduced in the 106th Congress in 1999, this bill has been introduced in five successive Congresses gaining increasing support in each. In the 110th Congress ETHA was introduced in the Senate by lead sponsors Senator Gordon Smith (R-OR) and Senator Hillary Rodham Clinton (D-NY) and currently has 32 co-sponsors (4 Republicans, 27 Democrats, and 1 Independent). In the House, the bill was introduced by lead sponsors Speaker Nancy Pelosi (D-CA) and Reps. Ileana Ros-Lehtinen (R-FL) and Eliot Engel (D-NY). To date, the bill has 54 original co-sponsors made up of 27 Democrats and 27 Republicans.

ETHA provides a more comprehensive approach to expanding Medicaid for people living with HIV than either the Ticket to Work Act or Section 1115 waivers. ETHA would allow non-disabled individuals to access Medicaid by creating another category of eligibility based solely on HIV status. While ETHA would not change the traditional asset limits, it would allow states to adopt higher income limits for persons with HIV. Ultimately, all low-income individuals who meet a state's financial eligibility requirements would be eligible for Medicaid benefits from the moment they test positive for HIV.

One of the most important advantages of ETHA for people living with HIV is the optional prescription drug benefit that all states currently provide under Medicaid. Access to prescription drugs, specifically antiretroviral therapies, preserves the health of individuals living with HIV and reduces other health care costs associated with opportunistic infections and co-morbidities. Further, expanding Medicaid through ETHA would transition a number of individuals to the Medicaid system, freeing up additional resources from other public programs such as the AIDS Drug Assistance Program (ADAP). State Medicaid programs have the potential to purchase discounted antiretroviral drugs at lower costs than ADAP.

States would also benefit directly from ETHA because the legislation provides an enhanced FMAP for HIV/AIDS care. This means that states will receive a higher reimbursement from the federal government to provide HIV related care and will expend comparatively fewer dollars on Medicaid for people living with HIV/AIDS than the rate for general disability status.

Ultimately, ETHA would eliminate some of the barriers that low-income, uninsured individuals living with HIV face in accessing health care and prescription drugs. By creating an additional Medicaid eligibility category, ETHA would offer substantial health care benefits for people living with HIV. Further, ETHA could serve as an early intervention program designed to delay the progression from HIV to AIDS. Individuals would be encouraged to get tested for HIV and seek medical care, if they know they will be eligible to receive treatment through a program such as ETHA. In this way, ETHA could improve the quality of life for individuals living with HIV and save on the costs associated with more complicated and expensive late stage treatment.

Health care costs associated with HIV/AIDS are highest after an AIDS diagnosis and skyrocket to between \$20,368 and \$29,515 per month in the final months before death²⁰. Under ETHA, Medicaid could provide treatment that would offset costs associated with non-drug services related to an AIDS diagnosis. Further cost savings would extend beyond Medicaid to other federal savings, such as costs saved by Ryan White programs. Finally, cost savings to the entire federal government in areas unrelated to health care would also be possible under ETHA.

According to a PricewaterhouseCoopers (PWC) five and ten year Cost Benefit Analysis, there are benefits to enacting ETHA in terms of lives saved, slower disease progression, and multiple federal programs offsets. The potential number of lives saved is truly dramatic.

If ETHA were enacted, there would be a 50% reduction in death rates of HIV infected Medicaid beneficiaries. PWC's analysis shows if ETHA were to pass, the death rate of HIV positive participants over ten years would be six percent. Without ETHA, the death rate over ten years would be 12%.²¹

As well as keeping thousands of people alive, ETHA would also be able to keep thousands more people healthy. ETHA would greatly improve Medicaid

participants CD4 levels. PWC estimates that over five years of current Medicaid eligibility criteria, about 21% of participants have a CD4 level of 50 or less. ETHA would decrease that rate to 17% or lower. Over an entire ten-year period of ETHA, around 77,000 participants would have CD4 levels above 500 compared to only 42,000 under current Medicaid estimates²². The ability to improve the quality and length of HIV positive individual's lives is the most compelling reason to enact ETHA, but the advantages of ETHA go beyond these important social benefits.

ETHA would also bring many benefits in terms of Federal cost savings. ETHA would provide savings in Medicaid, Medicare, SSI, SSDI, and Federal taxes. All of these savings would occur as a direct result of people staying healthy longer which in turn leads to fewer people becoming disabled and those who do, becoming disabled later. It is critical to factor all of these offsets and savings into any analysis of the costs of ETHA.

The PWC analysis states that over ten years the enactment of ETHA would save the federal government \$31.7 million dollars.²³ ETHA would cost more in the beginning of the program, with the cost savings taking several years to manifest. For this reason, ETHA has been painted as an expensive expansion of Medicaid when in fact it would lead to federal government savings.

Conclusions

In accessing health care through Medicaid, the greatest challenge for low-income individuals living with HIV is meeting the program's limited eligibility requirements. The only avenue of eligibility that is currently available for many HIV positive people—no matter what their

poverty level—is total disability status, as determined by the Social Security Administration. This requirement, which forces people to wait until they are disabled by AIDS to get help, robs many low-income individuals of the benefits provided by advances in HIV treatment. HIV treatment is most effective at preventing the decline of the immune system and subsequent infections when started early in the disease process.

Passage of ETHA must not supplant continued support of Ryan White programs. Instead, it should complement these services. By freeing up dollars from Ryan White programs such as ADAP and Title III (Part C), ETHA would allow health care access for more people. Further, those receiving health care through ETHA, and subsequently through Medicaid, would continue to rely on RWCA programs to meet other critical needs.

AIDS Action Position

- AIDS Action supports the passage of ETHA to allow states the option of extending Medicaid to people living with HIV who would not otherwise qualify.
- AIDS Action supports wide co-sponsorship of ETHA.
- AIDS Action believes it is critical to ensure that the optional prescription drug benefits provided under Medicaid are not limited for people living with HIV.
- AIDS Action believes that Medicaid expansion through ETHA must not supplant other programs providing care for people living with HIV/AIDS, including the Ryan White CARE Act.

¹ Early Treatment for HIV Act of 1999, H.R. 1591, 106th Cong., 1st Sess. (1999) /

Early Treatment for HIV Act of 1999, S. 902, 106th Cong., 1st Sess. (1999).

² Early Treatment for HIV Act of 2001, H.R. 2063, 107th Cong., 1st Sess. (2001) /

Early Treatment for HIV Act of 2001, S. 987, 107th Cong., 1st Sess. (2001).

³ Early Treatment for HIV Act of 2004, H.R. 3859, 108th Cong., 2nd Sess. (2004) /

Early Treatment for HIV Act of 2003, S. 847, 108th Cong., 1st Sess. (2003).

⁴ Early Treatment for HIV Act of 2005, S. 311, 109th Cong., 1st Sess. (2005).

⁵ Early Treatment for HIV Act of 2007, H.R. 3326, 110th Cong., 1st Sess. (2007) /

Early Treatment for HIV Act of 2007, S. 860, 110th Cong., 1st Sess. (2007).

⁶ Breast and cervical cancer prevention and treatment act of 2000, Pub. L. No. 106-354 (2000).

⁷ U.S. Department of Health and Human Services. (2006). *Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents*. Retrieved October, 2007, from US HHS Web page: <http://aidsinfo.nih.gov/contentfiles/AdultandAdolescentGL.pdf>

⁸ CRS Report for Congress. (2005) *Federal Medical Assistance Percentage (FMAP) for Medicaid*. Retrieved October, 2007, from University of Maryland Law School Web page: <http://www.law.umaryland.edu/marshall/crsreports/crsdocuments/RS2126203012005.pdf>

⁹ Centers for Medicare and Medicaid. (2000) *A Profile of Medicaid*. Retrieved October, 2007, from CMS Web Page: <http://www.cms.hhs.gov/TheChartSeries/Downloads/2Tchartbk.pdf>

¹⁰ Ibd

¹¹ Kates, Jennifer. (2004). *Financing HIV/AIDS Care a Quilt with Many Holes*. Retrieved October, 2007, from Kaiser Family Foundation Web page: <http://www.kff.org/hiv/aids/upload/Financing-HIV-AIDS-Care-A-Many-Holes.pdf>

¹² The Henry J. Kaiser Family Foundation. (2006) *Fact Sheet: Medicaid and HIV/AIDS*.

Retrieved October, 2007, from The Henry J. Kaiser Family Foundation Web page: <http://www.kff.org/hiv/aids/upload/7172-03.pdf>

¹³ Social Security Administration. (2002). *What we mean by i disability.i*

Retrieved October, 2007 from SSA Web page :<http://www.ssa.gov/dibplan/dqualify4.htm>

¹⁴ U.S. Department of Health and Human Services. (2006). *Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents*. Retrieved October, 2007, from the US HHS Web page: <http://aidsinfo.nih.gov/contentfiles/AdultandAdolescentGL.pdf>

¹⁵ Schackman, B. et al. (2006) The Lifetime Cost of Current Human Immunodeficiency Virus Care in the United States. *Medical Care*, 44 (11).

¹⁶ The Henry J. Kaiser Family Foundation. (2003) *Section 1115 Medicaid and SCHIP Waivers: Policy Implications of Recent Activity*. Retrieved October, 2007, from KFF Web page: <http://www.kff.org/medicaid/upload/Section-1115-Medicaid-and-SCHIP-Waivers-Policy-Implications-of-Recent-Activities-Policy-Brief.pdf>

¹⁷ The Henry J. Kaiser Family Foundation. (2004) *Status of State Medicaid Expansion Efforts for People with HIV*. Retrieved October, 2007, from KFF Web page: <http://www.statehealthfacts.org/comparatable.jsp?ind=565&cat=11>

¹⁸ Ticket to work and work improvement incentives act of 1999, Pub. L. No. 106-170 (2000)

¹⁹ Health Resources and Services Administration. (2007) *Medicare Part D Drug Benefit and HIV Car*. Retrieved October, 2007, from HRSA Web page: <http://www.hrsa.gov/medicare/HIV/overviewsidesSHORT.htm>

²⁰ Schackman, B. et al. (2006) The Lifetime Cost of Current Human Immunodeficiency Virus Care in the United States. *Medical Care*, 44(11)

²¹ Rodgers, Jack. (2003) *An Analysis of The Early Treatment for HIV Act*. Retrieved October, 2007, from Treatment Access Expansion Project Web page: <http://www.taepusa.org/documents/PWC%20Report%20-%20Final%20PDF.pdf>

²² Ibd

²³ Ibd